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IN THIS ISSUE:

- Approximately 126 infants born each year in Alaska are identified as having been affected by maternal alcohol use during pregnancy.
- During 1995 through 1998, an average of 14 Alaskan infants per year were born with Fetal Alcohol Syndrome (1.4 per 1000 live births).
- FAS surveillance resulted in higher FAS prevalence findings than previously reported for Alaska Natives - 4.8 per 1000 live births for children born in 1995 through 1998.
- Women 30 years of age or older are significantly more likely to have an FAS child than younger women.

Fetal Alcohol Syndrome Prevalence in Alaska: New Findings From The FAS Surveillance Project

Background

Fetal Alcohol Syndrome (FAS) was first identified as a clinical condition in 1973. FAS has drawn considerable attention in Alaska. During the 1980's, the Alaska Area Native Health Service of the Indian Health Service began FAS surveillance among beneficiaries. In 1990, the Alaska Area Native Health Service joined the Alaska Department of Health and Social Services and the Centers for Disease Control and Prevention in establishing the Alaska FAS Prevention Project. The Alaska FAS Prevention Project developed methods for FAS case identification from multiple data sources, documented issues associated with improved FAS surveillance and published the first population-based FAS prevalence for the state[1].

The Section of Maternal, Child and Family Health established the Alaska Fetal Alcohol Syndrome Surveillance Project in 1998. The Surveillance Project is part of a collaborative effort with the Centers for Disease Control and Prevention (CDC) and four other states (NY, WI, CO, AZ). These five states make up the National FAS Surveillance Network (FASSNet). FASSNet has developed a standardized surveillance case definition for FAS surveillance[2]. Participating states (with the exception of Wisconsin) use the same case definition and the same case abstraction methods; however, each of the five states uses varying methodologies for identifying potential FAS cases. FASSNet will soon publish surveillance findings for birth years 1995-97 in the CDC's Morbidity and Mortality Weekly Report. This issue of the Dataline summarizes FAS prevalence in Alaska for birth years 1995 through 1998.

Methods

FAS surveillance in Alaska is based on reports to the Alaska Birth Defects Registry. The Alaska Birth Defects Registry is population-based and uses a multiple source methodology for recording all reportable birth defects. The FAS Surveillance Project and the Alaska Birth Defects Registry are housed in the Division of Public Health's Section of Maternal Child and Family Health, MCH Epidemiology Unit.

Children reported to the Alaska Birth Defects Registry with the International Classification of Diseases, 9th revision (ICD-9) code 760.71 (infant affected by prenatal alcohol exposure) or 742.1 (child with microcephaly) are considered to be potential cases of FAS. Trained medical record abstractors review the medical records of each potential case. Extensive medical and risk factor information abstracted from medical records for each reported child is entered into standardized abstraction software developed by the CDC FASSNet group.

FAS surveillance case definitions were developed by FASSNet, in consultation with a committee of dysmorphologists, pediatricians, psychologists, epidemiologists, and public health officials. The FASSNet database uses an algorithm for determining FAS case status based on abstracted information. The case categories established by FASSNet are:

- Confirmed FAS phenotype with or without confirmed maternal alcohol exposure
- Probable FAS phenotype with or without confirmed maternal alcohol exposure; and
- Suspect FAS (reported children who do not meet the criteria for a confirmed or probable case).

To meet the criteria for confirmed FAS phenotype, a child must have medical record documentation of the following: facial features associated with FAS (small palpebral fissures, thin upper lip and smooth/abnormal philtrum); central nervous system impairment, either structural or functional (head circumference less than or equal to the 10th percentile at birth, low intellectual functioning, developmental delay, mental retardation, or attention deficit disorder); and height, weight or weight for height below the 10th percentile for age. Probable FAS phenotype differs from the confirmed FAS phenotype in that a child may have either central nervous system impairment, or height and weight below the 10th percentile in addition to the facial features associated with FAS.

In this report all children who were reported to the Alaska Birth Defects Registry with ICD-9 codes 760.71 or 742.1, and for whom a medical chart review was conducted, are described as "at risk of FAS." An "FAS case" is defined as a child who was classified as confirmed or probable according to the definitions above.

Records of children identified as being at risk for FAS were linked to birth certificates to eliminate duplicate cases and to obtain additional epidemiological information. Birth certificate data were used to compute rate ratios (rr) for potential maternal risk factors and to compare the prevalence of adverse birth outcomes among FAS cases with other Alaskan children born during the study period (1995 through 1998).

Results

As of July 1, 2001, 543 Alaska children, born in 1995-98, were reported to the Alaska Birth Defects Registry as potential FAS cases. Of the 543 children, 505 (93%), had at least one medical chart abstraction. Among these 505 children, 55 met the FAS surveillance case definition for either a confirmed or probable case.

Table 1. FAS Surveillance Case Finding Results, by Birth Year, Alaska, 1995-98.

Birth Year	Children At Risk of FAS	Confirmed FAS Cases	Probable FAS Cases	Total FAS Cases	Percent of At Risk Children with FAS
1995	67	9	6	15	22.4
1996	126	14	4	18	14.3
1997	138	9	4	13	9.4
1998	174	6	3	9	5.3
Total	505	38	17	55	10.9

Table 2. FAS Prevalence by Mother's Race, Alaska, 1995-98.

Mother's Race	Children At Risk of FAS			Children with FAS		
	n	Rate per 1000 Live Births	95% Confidence Interval	n	Rate per 1000 Live Births	95% Confidence Interval
White	74	2.7	(2.1, 3.4)	5	0.2	(0.0, 0.3)
Alaska Native	390	40.9	(36.9, 45.0)	46	4.8	(3.4, 6.2)
African American	5	2.9	(0.4, 5.4)	0	-	-
Asian/Pacific Islander	9	4.6	(1.6, 7.5)	0	-	-
Unknown	27	-	-	4	-	-
Total	505	12.6	(11.5, 13.6)	55	1.4	(1.0, 1.7)

The proportion of children reported "at risk of FAS" who met the case definition decreased for each subsequent birth year (Table 1). The overall FAS prevalence for Alaska, for children born in 1995-98, was 1.4 per thousand live births (95% C.I.: 1.0 – 1.7).

All races were represented among children who were reported "at risk of FAS", but only whites and Alaska Natives met the FAS surveillance case definition. Children born to Alaska Native women were significantly more likely to be reported to the Alaska Birth Defects Registry as having an alcohol related birth defect than children of other races. Among the 55 children with confirmed or probable FAS, 84% were Alaska Natives and 9.1% were white (Table 2).

Maternal characteristics (as indicated on the birth certificate) that were associated with having a child with FAS were: alcohol use during pregnancy, cigarette smoking during pregnancy, Alaska Native race, maternal age of 30 or more years, and 12 or fewer years of education. Maternal residence in Anchorage or Fairbanks, the two census areas in Alaska with the largest populations, was not associated with FAS (Table 3).

Twenty-two percent of children with FAS were born at less than 33 weeks gestation and 25% were born between 33 and 37 weeks of gestation. Fifty percent of children with FAS were born with low birth weight. The prevalence of low birth weight and prematurity were significantly higher among children with FAS than other infants born over the study period (relative prevalence = 8.9 (95% CI: 6.7,11.9) and 4.8 (95% CI: 3.6, 6.4) respectively). FAS was not associated with sex of the child.

Discussion

The statewide FAS rate presented in this report (1.4 per 1000 children born in 1995-98) is higher than that found previously by the Alaska FAS Prevention Project (0.8 per 1000 children born in 1977-92)[3]. Differences in the case finding methodology used by the two projects may have contributed to the higher rate found by the Alaska FAS Surveillance Project. Routine public health surveillance provides a system for identification of all potential cases based on standardized surveillance protocols. Ongoing surveillance also provides for systematic updates to the FAS prevalence for any given birth cohort. Children may not be diagnosed with FAS or reported "at risk of FAS" until they are as old as six years; additionally, future medical chart abstractions on children previously reported to the registry may change case status findings. Because of this, the Alaska FAS Surveillance Project may report higher FAS prevalence in the future as the birth cohort ages.

Our surveillance findings substantiate previous reports that Alaska Natives have a vastly higher reported prevalence of FAS than other races[3,4,5]. Increased awareness of maternal alcohol use and excellent documentation by Alaska Native health organizations may result in more vigilant reporting of potential cases of FAS. Diagnostic bias may also play a role in explaining the high FAS rate for Alaska Natives: growth curves for Yup'ik Eskimos, one of the largest Alaska Native groups, indicate that this group tends to have shorter stature than the standard US population (State of Alaska, unpublished data). Furthermore, some Yup'ik Eskimo facial features resemble those characteristic of FAS, such as small palpebral fissure.

Another finding of this study that is substantiated by previous reports is the association of older maternal age with FAS. This

study demonstrates that while the association holds true for FAS cases, there is no significant association with maternal age among children who are reported to the Alaska Birth Defects Registry as "at risk" for FAS. These findings suggest that maternal age may be a co-factor in the risk of developing symptoms consistent with FAS. Further study of the interaction between risk factors, such as age, race and maternal alcohol use during pregnancy is needed. Continued collection and analysis of FAS surveillance data over time will increase the power of risk factor analysis.

This analysis showed that children whose birth certificate's recorded maternal alcohol use during pregnancy were 51 times more likely to have FAS. The birth certificates of 15 of the children who met the case definition for FAS did not record maternal alcohol use. Retrospective assessment of maternal alcohol use is difficult; birth certificate information may be unsubstantiated and often, the medical charts of children reported to be at risk of FAS do not contain adequate information on maternal drinking. Interestingly, data from a population based survey of women who have recently had a live birth in Alaska show 3.7% of Alaska Native women reported drinking during the last three months of pregnancy compared to 4.6% of white women.[6]

Because the FAS rates reported here are derived from surveillance data, they are affected by the degree to which health care providers comply with birth defects reporting requirements. It is important to recognize that the

Table 3. FAS Risk Ratios (rr) for Selected Maternal Characteristics, from Linked Birth Certificate Information, Alaska, 1995-98.

Potential Risk Factor	Children with FAS		
	n	Rate per 1,000 Live Births	rr (95% CI)
Maternal Race			
Alaska Native	46	4.8	29.6 (11.76, 74.42)*
Non-Native	5	0.2	ref.
Maternal Age			
>= 30 years	37	2.6	4.9 (2.68, 9.15)*
< 30 years	14	0.5	ref.
Maternal Residence			
Anchorage or Fairbanks	27	1.6	1.5 (0.89, 2.66)
Other Regions	24	1.0	ref.
Maternal Education			
High School or less	38	1.7	5.0 (2.1, 11.7)*
More than High School	6	0.4	ref.
Smoked during Pregnancy			
Yes	39	5.0	16.2 (8.1, 32.5)*
No	10	0.3	ref.
Alcohol Use During Pregnancy			
Yes	32	19.9	50.6 (27.5, 93.2)*
No	15	0.4	ref.

*Statistically significant

ICD-9 code 760.71 is not specific to FAS. This code means only that an infant has been identified as having been prenatally affected by maternal alcohol exposure, and may or may not be identified at birth or in later years as a child with FAS. The relative interpretation of which cases to report under ICD-9 code 760.71 effects the sensitivity and specificity of FAS surveillance. Efforts to increase awareness and understanding of mandated birth defects reporting should be continued.

The proportion of FAS cases among children reported as "at risk of FAS" decreased for each successive birth year under study. Children reported at birth with maternal alcohol exposure may not initially meet the FASSNet case criteria, but may meet the definition later in life. Many tests and assessments for developmental delay may not be effective until after a child has reached the age of three or older. Since most children with FAS are diagnosed between ages 3 and 5, the prevalence of FAS for any given birth year may increase as the birth cohort ages. This illustrates the importance of abstracting medical data over time for children reported with prenatal alcohol exposure. An important feature of the Alaska FAS

Surveillance Project is our ability to continue medical chart abstraction for all children reported at risk of FAS up to the sixth birthday. Completion of medical chart abstractions for all reported children and follow-up abstractions on suspect cases is a central component of on-going FAS surveillance.

FAS prevalence in Alaska is higher than in other FASSNet regions.[7] In the first FASSNet report on FAS prevalence, estimates of FAS prevalence for birth years 1995-97 ranged from 0.26 per 1000 in the Denver-Boulder metropolitan area, to 1.5 per 1000 in Alaska. For Alaska Natives the FAS prevalence is 5.6 per 1000 live births for birth years 1995-97. We found a similar overall FAS prevalence in our analysis of children born in 1995-98 (1.4 per 1000) but a lower prevalence for Alaska Natives (4.8 per 1000). The higher race-specific finding in our FASSNet report for birth years 1995-97 illustrates how case ascertainment may be more complete for older birth cohorts.

Alaska's high FAS prevalence and the presence of ongoing surveillance provide the opportunity to implement and monitor intervention programs. The relatively small number of women who give birth to children with FAS may make targeted intervention programs the most cost-effective method of decreasing FAS prevalence. Future analysis of FAS surveillance data on maternal characteristics of mothers of children with FAS will help to focus these efforts.

Recommendations

- The Alaska Birth Defects Registry should continue provider education efforts to encourage consistent and timely compliance with birth defects reporting requirements.
- Health care providers should be encouraged to document the details of maternal alcohol use during pregnancy in the child's medical chart.
- The Fetal Alcohol Syndrome Surveillance Project should implement a plan for completion of medical chart abstractions for all reported children and for routine and follow-up abstractions on suspect cases.
- The Section of Maternal Child and Family Health should conduct further study of the interaction between FAS risk factors.
- The Section of Maternal Child and Family will monitor trends in FAS prevalence through periodic analysis of FAS surveillance data.
- The Section of Maternal Child and Family Health should work with the Office of FAS to develop mechanisms to make FAS surveillance findings widely available to prevention programs for use in planning and evaluation.

Submitted by Janine Schoellhorn and Danise Podvin

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